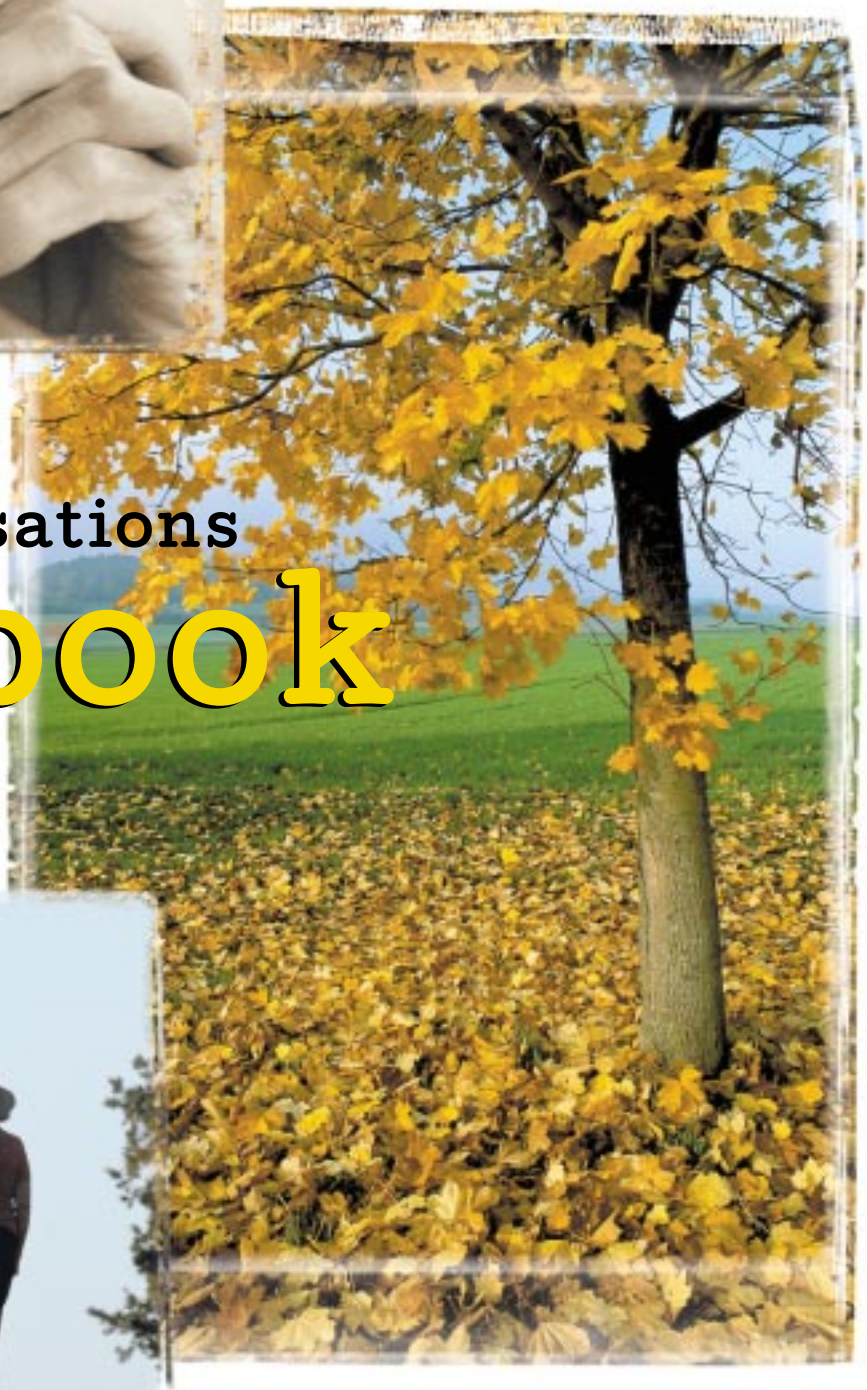

Caring Conversations workbook

Caring conversations℠

making your wishes known for end-of-life care

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Order Information

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Caring Conversations workbooks are available for individual purchase, for institutional use, or as part of the *Caring Conversations* program. For more information about the *Caring Conversations* program, call Midwest Bioethics Center at (816) 221-1100 or fax your request to (816) 221-2002.

Caring Conversations Preface

We live within webs of social relationships — family, school, work, faith. We mark many of the predictable landmarks of our lives with social rituals — birthdays, graduations, weddings, retirements, burials. However, social rituals that mark life's last chapter are uncommon. Without such rituals, the end of life in America is marked in other ways. Patients suffer in pain that could and should be managed. Seriously ill patients and their families needlessly suffer spiritual, psychological, and social distress. Too often, the financial costs of caring for dying patients are catastrophic, but the benefits of the care are marginal. Preferences concerning care at the end of life are not expressed or heard, or they are heard but not respected. The value of life's last chapter may be missed entirely.

This *Caring Conversations* workbook provides a social ritual that helps loved ones plan for the end of life. Sharing the information in *Caring Conversations* allows others to understand and respect the preferences of patients who can no longer speak for themselves and eases the tension that patients and their families experience during a last illness. This workbook is intended to help you, your family, and your friends think about these issues now, while you are able to respond to specific questions. Sharing the workbook now will help you and your loved ones find peace of mind in the future.Your preferences may change over time, so revisit your workbook regularly and modify it as necessary. We invite you to use the workbook to prepare yourself and others for your personal ritual of *Caring Conversations*.

Caring Conversations Questionnaire

For many people, the end of life is a call to complete unfinished business. It offers a time and opportunity to reexamine the relationships, events, values, and tasks that are most important to us — the people and "things" with whom and for whom we have lived our lives, and in whose care we are most likely to experience our final days. Preparing for this time is difficult because decisions have to be made. *Who am I? Who is important in my life? Who do I want near me, or do I want to be alone?*

This workbook provides a series of questions to help you think about your future, make decisions, and communicate them to your loved ones and those whom you will choose to act for you if you cannot speak for yourself. You may want to complete this book alone, before you have a caring conversation. Or you may choose to fill it out with someone during a caring conversation. But even if you have already shared these thoughts, we urge you to talk about them again from time to time. Caring conversations affirm life; they ensure that your values and preferences will be known, remembered, and honored.

As you consider the following questions, imagine that you are in the last six months of your life. Use additional paper as needed and skip any questions you are not ready to answer.

- With whom do you want to have caring conversations?

- What do you most want to say to them?

- When and where will you have your caring conversations?

- What life events have given you the most joy?

- What life events have saddened you the most?

- What beliefs do you hold that influence your thoughts about life and your thinking about dying?

- What concerns do you have about your health or future healthcare?

- What are your fears regarding the end of your life?

- What do you most value about your physical or mental well being? (Do you love to be outdoors? Does being able to read or listen to music bring you pleasure? How important is it to be aware of your surroundings and the people with you? How important is seeing, tasting, touching?)

- Are there circumstances under which you would refuse or discontinue treatment that might prolong your life? If so describe those circumstances.

- If you could plan it today, what would the last day of your life be like? (Where would you be? What would you be doing? What would you eat? What music would you listen to? What would be your final words and your last acts?)

- How do you want to be remembered?

- If you wrote your own epitaph or obituary, what would it say?

Personal/Relationships

In his book, Dying Well, *Ira Byock suggests five phrases about which dying people want to have caring conversations. They are "I forgive you. Please forgive me. I love you. Thank you. Good-bye." Consider these phrases as you answer the following questions.*

- Are there people to whom you want to write a letter or for whom you want to prepare a taped message, perhaps marked for opening at a future time?

- Are there special ways you want to share time with friends and family? (Do you, for example, want to have a private good-bye visit with some of the special people in your life?)

- Would you want to make a final trip to visit family, friends, or a special place? (If so, where would you go? What would you do? With whom would you go?)

- Do you want to have a special ritual gathering such as a prayer service, perhaps sharing memories or songs?

- What are your thoughts about your memorial service? (Do you have any favorite songs or readings? Are there specific people you hope will participate?)

Spiritual/Religious Values

• How would you describe your spiritual or religious life?

• What gives your life its purpose and meaning?

• What is important for others to know about the spiritual or religious part of your life?

• If forgiveness is important to you, how will you seek it, and from whom?

• What do you need for comfort and support as you journey near death? (Do you want to pray with a member of the clergy, be read to from spiritual or religious texts, or listen to poetry or tapes?)

Healthcare Decisions

- Who would you want to make healthcare decisions for you if you could not make them for yourself? What is his or her relationship to you?

_____
_____
_____
_____

- Who would be your second choice?

_____
_____
_____

- Where do you want to be and what things do you need to be comfortable as you die? (Would you like to be in a hospital, a special place, or at home? Is it important to have sunlight or fresh breezes? To be free of uninvited guests? To be held? To be alone? To review family traditions? To listen to music?)

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

- Would you want to be sedated if it were necessary to control your pain?

_____
_____
_____

- If you could no longer swallow, would you want tube feedings?

_____
_____

- Would you want to have a hospice team or other palliative (i.e., comfort) care available to you?

_____
_____

- Would you want treatments that might prolong your life if you were . . . (circle your response)

No longer able to think for yourself?
Yes No

Comatose and not likely to regain consciousness?
Yes No

Terminally ill or near death?
Yes No

Of very advanced age?
Yes No

- What does "very advanced age" mean to you?

_____
_____
_____
_____

- Do you wish to donate your organs and tissue?

_____
_____

- Do you want to donate your body to science for medical education? If yes, what institution?

_____
_____
_____

- Would you agree to an autopsy?

_____
_____

- Do you prefer burial or cremation?

_____
_____

Career and Work Decisions

- Goals to be achieved

- Duties to be delegated

- Projects to be finalized

Legal Documents

- Documents to be prepared (e.g., wills, trusts, powers of attorney, healthcare directives)

- Documents to be shared with others (e.g., bank account and safety deposit box information, insurance policies, stock certificates, deeds, titles)

Financial Matters

- Transferring property

- Meeting financial obligations

- Providing for your dependents

- Making charitable contributions

Conclusion

Having caring conversations can provide confidence and peace of mind to those faced with making decisions for loved ones at the end of life. The next section of this workbook includes an advance directive document for your use. It is a legal document that is valid in any state as long as it is notarized, signed, and witnessed. We encourage you to complete this form and give copies to your healthcare provider and family members. We also encourage you to continue having caring conversations. Your preferences and wishes may change over time, but making your desires known will give you and your loved ones peace of mind as you near the end of life.

Advance Directives for Health Care: Michigan's Patient Advocate Law

QUESTIONS AND ANSWERS
Advance Directive for Health Care

1. What is an "advance directive"?

An advance directive is a written document in which a competent individual gives instructions about his or her health care, that will be implemented at some future time should that person lack the ability to make decisions for himself or herself.

2. Must I have an advance directive?

No. The decision to have an advance directive is purely voluntary. No family member, hospital, or insurance company can force you to have one, or dictate what the document should say if you decide to write one.

3. Are there different types of advance directives?

Yes. There are three types: a durable power of attorney for health care, a living will, and a do-not-resuscitate order. Living wills are not recognized in Michigan, but can provide helpful guidance to healthcare providers, patients, and families. In addition, they may be used as evidence in court if there is a dispute as to your health care desires. If you are unable to participate in your health care decision, and there is a dispute over your wishes, living wills or other written or oral statements may be used as evidence to help the court determine your health care wishes. You may wish to consult an attorney for further information regarding durable powers of attorney or living wills.

4. What is a "durable power of attorney for health care"?

A durable power of attorney for health care, also known as a health care proxy, is a document in which you give another person the power to make medical treatment and related personal care and custody decisions for you.

5. Is a durable power of attorney for health care legally binding in Michigan?

Yes, based on a state law passed in 1990, called the Designation of Patient Advocate.

6. Who is eligible to create a durable power of attorney for health care?

Anyone who is 18 years of age or older and of sound mind is eligible.

7. What is the title of the person to whom I give decision-making power?

That person is known as a "patient advocate."

8. Who may I appoint as a patient advocate?

Anyone who is 18 years of age or older may be appointed. You should choose someone you trust, who can handle the responsibility, and who is willing to serve.

9. Does a patient advocate need to accept the responsibility before acting?

Yes, he or she must sign an acceptance. This does not have to be done at the time you sign the document. Nevertheless, you should speak to the person you propose to name as patient advocate to make sure he or she is willing to serve.

10. When can the patient advocate act in my behalf?

The patient advocate can make decisions for you only when you are unable to participate in medical treatment decisions.

11. Why might I be unable to participate in medical treatment decisions?

You may become temporarily or permanently unconscious from disease, accident or surgery. You may be awake but mentally unable to make decisions about your care due to disease or injury. In addition, you might have a temporary loss of ability to make or communicate decisions if, for example, you had a stroke. Others might suffer long-term or permanent loss through a degenerative condition such as Alzheimer's disease.

12. Who determines that I am no longer able to participate in these decisions?

Your attending physician and one other physician or licensed psychologist will make that determination. If your religious beliefs prohibit an examination to make this determination, and this is stated in the designation document, you must indicate in the document how it would be determined when the patient advocate exercises powers concerning decisions on your behalf.

13. What powers can I give a patient advocate?

You can give a patient advocate the power to make those personal care decisions you normally make for yourself. For example, you can give your patient advocate power to consent to or refuse medical treatment for you, to arrange for home health care or adult day care, arrange care in a nursing home, or move you to a home for the aged. According to state law, if you were to become incompetent while pregnant, your patient advocate could not authorize a medical treatment decision to withhold or withdraw treatment from a patient who is pregnant that would result in the pregnant patient's death.

14. Can I give my patient advocate the authority to make decisions to withhold or withdraw life-sustaining treatment, including food and water administered through tubes?

Yes, but you must express in a clear and convincing manner that the patient advocate is authorized to make such decisions, and you must acknowledge that these decisions could or would allow your death. If you have specific desires as to when you want to forego life-sustaining treatment, you should describe in the document the specific circumstances in which he or she can act. You may also include them as written instructions in your durable power document.

15. Do I have the right to express in the document my wishes concerning medical treatment and personal care?

Yes. You might, for example, express your wishes concerning the type of care you want during terminal illness. You might also express a desire not to be placed in a nursing home and a desire to die at home. Your patient advocate has a duty to try to follow your wishes.

16. Is it important to express my wishes in the durable power of attorney for health care designating document?

Yes. Your wishes might not be followed if others are unaware of them. It can also be a great burden for your patient advocate to make a decision for you without your specific guidance.

17. Can I appoint a second person to serve as patient advocate in case the first-named person is unable to serve?

Yes.

18. Must a durable power of attorney for health care designation document be witnessed?

Yes. A designation must be executed in the presence of and signed by two witnesses. The witnesses must not include your spouse, parent, child, grandchild, sibling, presumptive heir, known devisee at the time of the witnessing, physician, or patient advocate; an employee of your life or health insurance provider; an employee of a health facility that is treating you; or an employee of a home for the aged as defined in section 20106 of the Public Health Code, Act No. 368 of the Public Acts of 1978, being Section 333.20106 of the Michigan Compiled Laws, where you reside.

19. In general, what should I do before completing an advance directive?

Take your time. Consider who you might choose to be your proxy, or to act in your place. Think about your treatment wishes. Discuss the issue with family members. Talk with your minister, rabbi, priest, or other spiritual leader if you feel it would be helpful. Bring the subject up with your doctor. Have a discussion about benefits and burdens of various types of treatment.

20. Are there issues I should give particular attention to?

Yes. Many people have strong feelings about the administration of food and water, either by tube down their throat, a tube placed surgically into their stomach, or intravenously. You may wish to consider and indicate in what circumstances, if any, you wish such procedures withheld or withdrawn. Also, bear in mind that people's opinions regarding their own health care may change over time. Your wishes regarding medical treatment when you are relatively young may be quite different from your wishes when you reach advanced age, so you may wish to review your decisions periodically with your patient advocate.

21. Is there a standard form for an advance directive?

Absolutely not. While this pamphlet contains a sample form which you may choose to use to designate a patient advocate, you may use a form designed by an organization, you may hire a lawyer to draft the necessary documentation, or you may write out the document yourself. If you write the documentation yourself, make sure that it is legible. Under state law, the designation must be in writing, you must sign the document, date it, and have it witnessed as described above. A person accepting the responsibility to act as a patient advocate must sign an acceptance to the designation document which contains provisions required by statute. (These statutory provisions are listed in sections A through I found in part V of the attached Durable Power of Attorney for Health Care Form.)

22. What if there is a dispute as to how my durable power of attorney for health care should be carried out?

If there is a dispute as to whether your patient advocate is acting consistent with your best interest, the probate court may be petitioned to resolve the dispute. The court can remove a patient advocate who acts improperly in your behalf.

Guide for Using The Durable Power of Attorney Form

The pages following this guide contain a blank copy of a Durable Power of Attorney for Health Care form which you may use to designate your patient advocate. This is a suggested form only. Michigan law does not require a specific form to be used. If you wish to provide more details in your durable power document, you may attach additional pages to it containing those details. This guide is intended to help clarify the purposes of the various provisions in this form.

THIS FORM PROVIDES FOR A DURABLE POWER OF ATTORNEY FOR PURPOSES OF CARE, CUSTODY, AND MEDICAL TREATMENT ONLY. IF YOU DESIRE A MORE COMPREHENSIVE DURABLE POWER OF ATTORNEY THAT GRANTS AUTHORITY FOR PURPOSES OF HANDLING FINANCIAL OR BUSINESS AFFAIRS, PLEASE CONSULT AN ATTORNEY.

SECTION I: APPOINTMENT OF ADVOCATE

The first several blanks in the form are for putting your name and the name(s) of persons you are appointing as your advocate or successor advocate. You may appoint ANY person who is at least 18 years of age to be your advocate. It is important that you consult with the person you are naming and secure his or her consent before naming that person.

The law requires that before you can be considered unable to participate in medical treatment decisions, that determination must be made by your attending physician and at least one other physician or a licensed psychologist. Because some individuals' religious beliefs may not allow for an examination by a physician, the document can state the religious objection and indicate how it shall be determined when the patient advocate may exercise his or her powers.

SECTION II: GRANTS OF AUTHORITY AND RESPONSIBILITY

This is a crucial section of the durable power document. You may check any, all or none of the grants of power. If you do not check any of the options, you will need to attach your own written grants of power to indicate what powers your advocate will have.

This section contains the very important provision regarding whether decisions to withhold or withdraw treatment which would allow you to die will be made for you. Due to the serious nature of this granting of power, Michigan law requires that you express in a clear and convincing manner that your patient advocate is authorized to make such a decision, and that you acknowledge that such a decision could or would allow your death. If you do grant this authority, you should make clear to your advocate your desires for treatment. Section III of the form provides a space for setting forth your desires.

SECTION III: DESIRES AND PREFERENCES FOR TREATMENT

This is the section of the document where you may state your desires regarding the care, custody and medical treatment you should or should not receive, and under what circumstances treatment should be administered, continued, refused, or withdrawn. Here you may direct your treatment regarding mechanical life-supports (like respirators or kidney dialysis), ordinary routine treatments (simple surgeries, use of antibiotics, insulin, heart or blood pressure medications, etc.), and basic care (including the provision of food and water). As with the other sections of your durable power document, you may attach additional pages if the space provided is inadequate.

MICHIGAN LAW DOES NOT REQUIRE THAT YOU FILL OUT THIS SECTION OR PROVIDE AN ATTACHMENT ACCOMPLISHING THE SAME PURPOSE. The law stipulates that your advocate must act in your best interests and that health care providers should only comply with your advocate's direction if he or she is reasonably believed to be acting within the authority granted in your designation of the patient advocate. Thus, directions your advocate gives which are consistent with your statement in this section are not likely to be questioned.

SECTION IV: SIGNATURE AND WITNESSING

Michigan law requires that before a patient advocate can execute any of his or her duties and responsibilities, he or she must sign an acceptance to the designation. The first provision of Section IV simply insures that you are aware that this designation must be signed before the power of attorney becomes effective. It also will indicate whether the designation and acceptance process were completed at one time.

Next, your signature is required. Finally, the requirements pertaining to the witnessing of the designation are contained within this section. Please note the limitations on who may serve as a witness.

SECTION V: ACCEPTANCE OF THE DESIGNATION

As noted above, the advocate whom you name must sign an acceptance of your appointment before he or she can act on your behalf. Michigan law requires that certain information regarding the rights, authorities, and limits related to durable power designations be contained within this acceptance. The acceptance provided in Section V of the form meets these requirements. The name of the person you are appointing should appear in the first blank, and your name (principal) should appear in the second blank. The third blank should contain the date on which you signed your durable power document. The acceptance may be signed on the same day, or at a later time. Finally, your advocate's signature and the date of his or her signing are needed at the end of the acceptance.

Durable Power Of Attorney For Health Care

(Please print or type required information)

I. Appointment of Patient Advocate

I, _____
(Your full name)

of_____
(Your complete legal address)

hereby appoint _____
(Person you are appointing)

residing at _____
(Person's complete legal address)

as my patient advocate with the following power to be exercised in my name and for my benefit, for the purpose of making decisions regarding my care, custody and medical treatment. This durable power of attorney shall not be affected by my disability or incapacity, and is governed by Sections 700.5506 through 700.5512 of the Michigan Compiled Laws.

In the event that the above-named patient advocate is unable or expresses an intent not to serve as advocate, I then appoint

_____
(Name of successor)

residing at _____
(Legal address)
to serve as my patient advocate.

This durable power of attorney shall be exercisable (check one):

☐ When my attending physician and at least one other physician or licensed psychologist determine upon examination that I am unable to participate in medical decisions.

☐ If my religious beliefs prohibit my examination by a physician or licensed psychologist, then when the following events occur:

_____
_____
_____
(use attached sheets if necessary)

Before the powers granted in this durable power of attorney are exercisable, a copy of it shall be placed in my medical record with my attending physician and if applicable, with the facility where I am located. I retain the right to revoke this durable power of attorney at any time, and by any means whereby I may communicate an intent to revoke it.

II. Grants of Authority and Responsibility

With respect to my physical and medical treatment, I am granting to my advocate the authorities and responsibilities indicated below. Check those you are authorizing and add any additional authorities and responsibilities below. Use more sheets if necessary.

☐ Access to and control over my medical records and information.

☐ Power to employ and discharge physicians, nurses, therapists, and any other care providers, and to pay them reasonable compensation.

☐ Power to give informed consent to receiving any medical treatment or diagnostic, surgical, or therapeutic procedure.

☐ Power to refuse, or to authorize the discontinuance of, any medical treatment or diagnostic, surgical, or therapeutic procedure. IN GRANTING THIS POWER, I AUTHORIZE MY ADVOCATE TO MAKE A DECISION TO WITHHOLD OR WITHDRAW TREATMENT THAT WOULD ALLOW MY DEATH. I FURTHER ACKNOWLEDGE THAT SUCH A DECISION TO WITHHOLD OR WITHDRAW TREATMENT COULD OR WOULD ALLOW MY DEATH. I INSTRUCT MY ADVOCATE IN SECTION III, ON THE NEXT PAGE, AS TO MY DESIRES REGARDING THE WITHHOLDING OR WITHDRAWAL OF TREATMENT THAT COULD OR WOULD BRING ABOUT MY DEATH. (If you have checked this item, it is strongly recommended that you use the optional Section III on the next page to specify your desires.)

☐ Power to execute waivers, medical authorizations, and such other approval as may be required to permit or authorize care which I may need, or to discontinue care that I am receiving.

III. Desires and Preferences for Treatment (optional section) .
I understand that my inability to participate in medical treatment decisions may encompass a wide range of circumstances, including, but not limited to, my being either (a) conscious, but mentally incompetent, or (b) unconscious and unaware. In light of the wide range of circumstances which might effectuate this document, my desires and preferences for treatment include:

IV. Signature of Principal

I have discussed this designation with my above-named patient advocate who intends to sign the attached acceptance to this designation (check one):

☐ Concurrently with the execution of this document.

☐ At a future date.

I freely and voluntarily sign this document, in the presence of the below-named witnesses, and it shall become effective on the date indicated below.

_____

Your signature

_____

Date

_____

Print or type full name

_____

Address

_____

City, State, Zip

ATTESTATION OF WITNESSES

As a witness to the execution of this durable power of attorney, I attest that the person who has signed this document in my presence appears to be of sound mind and under no duress, fraud, or undue influence. I further attest that I am not the person's spouse, parent, child, grandchild, sibling, presumptive heir, known devisee at the time of this witnessing, physician, the named patient advocate, an employee of a life or health insurance provider for the person, or an employee of a health facility that is treating the person or a home for the aged where the person resides.

_____

First Witness's Signature

_____

Address

_____

Type or Print Name

_____

City, State, Zip

_____

Second Witness's Signature

_____

Address

_____

Type or Print Name

_____

City, State, Zip

V. Acceptance to the Designation of Power of Attorney

I, _____

Print patient advocate's name

hereby accept the responsibilities conferred upon me by

_____

Print principal's name

to serve as patient advocate in the durable power of attorney document executed on

_____

Date

I maintain the right to revoke this acceptance at any time, and by any means whereby I may communicate a desire to revoke it. By providing my signature below I acknowledge that I have read and understand the requirements of Michigan law pertaining to the execution of a durable power of attorney for health care, set out in sections (A) through (I) below.

A. This designation is not effective unless the patient is unable to participate in medical treatment decisions.

B. A patient advocate shall not exercise powers concerning the patient's care, custody and medical treatment that the patient, if the patient were able to participate in the decision, could not have exercised on his or her own behalf.

C. This designation cannot be used to make a medical treatment decision to withhold or withdraw treatment from a patient who is pregnant that would result in the pregnant patient's death.

D. A patient advocate may make a decision to withhold or withdraw treatment that would allow a patient to die only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision, and that the patient acknowledges that such a decision could or would allow the patient's death.

E. A patient advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a patient advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights and responsibilities.

F. A patient advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the patient and shall act consistent with the patient's best interests. The known desires of the patient expressed or evidenced while the patient is able to participate in medical treatment decisions are presumed to be in the patient's best interests.

G. A patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.

H. A patient advocate may revoke his or her acceptance to the designation at any time and in any manner sufficient to communicate an intent to revoke.

I. A patient admitted to a health facility or agency has the rights enumerated in section 20201 of the public health code, 1978 PA 368, MCL 333.20201.

Some, but not all, of the rights enumerated in Sec. 20201 include: A patient or resident in a health facility or agency (including a hospital or nursing home) will not be denied appropriate care on the basis of race, religion, color, national origin, sex, age, disability, marital status, sexual preference, or source of payment.

Patients and residents are also entitled to:

- inspect copies of their medical records and to have the confidentiality of those records maintained.
- receive adequate and appropriate care, and to receive from the appropriate individual within the facility, information about his or her medical condition, proposed course of treatment, and prospects of recovery, in terms which the patient or resident can understand.
- refuse treatment to the extent provided by the law and to be informed of the consequences of that refusal. When a refusal of treatment prevents a health facility or its staff from providing appropriate care according to ethical and professional standards, the relationship with the patient or resident may be terminated upon reasonable notice.

- information about the facility's policies and procedures for initiation, review, and resolution of patient complaints.
- receive and examine an explanation of his or her bill regardless of the source of payment and to receive, upon request, information relating to financial assistance available through the facility.
- associate and have private communications and consultations with his or her physician, attorney, or any other person of his or her choice, and to send and receive personal mail unopened on the same day it is received at the health facility or agency, unless medically contraindicated as documented by the attending physician in the medical record.

_____

Advocate's Signature

_____

Date

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